



Extended Research Article

Development of the best practice model to improve crisis management for older people with dementia: the AQUEDUCT mixed methods research programme including RCT

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Scientific summary

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Scientific summary

Background

Dementia is a significant threat to global health and a leading cause of disability and dependency among older people. Policy has focused upon 'living well with dementia', support for care at home and avoiding unnecessary admission to inpatient care. However, fluctuations in the health and social circumstances of the person with dementia and their family carers may lead to crisis, breakdown in home care and admissions to hospital or long-term care.

A variety of services have developed, usually part of multidisciplinary mental health teams, to respond to crises in dementia care. However, there is little evidence or guidance as to what constitutes best practice and effective service design to deliver good outcomes. There is some evidence that specialist crisis services can reduce hospital admissions, but more rigorous evidence and a clearer specification of best practice is required. Effective investment in such services needs a more defined service model, ways in which they operate and their impact. This was the remit of the Achieving Quality and Effectiveness in Dementia Using Crisis Teams (AQUEDUCT) programme.

Objectives

The overall programme aims were to improve the quality and effectiveness of care for people with dementia (PwD) and their carers experiencing a crisis; to achieve a reduction in hospital admissions; better experiences for PwD and their carers and a reduction in costs of care. It was divided into three work packages (WPs).

Specific objectives

Work package 1: investigation of best practice in Teams Managing Crisis in Dementia and development of the Best Practice Tool and Best Practice Resource Kit

- To determine best practice in Teams Managing Crisis in Dementia (TMCDs) by drawing on the perspectives and experiences of service users, carers, professionals and experts, and to synthesise this evidence.
- To formulate an evidence-based conceptual model and recommendations for achieving best practice in the organisation and operation of TMCDs to guide research and practice.
- To develop and validate a fidelity measure to assess to what extent TMCDs achieve best practice.
- To develop a Resource Kit for TMCDs to achieve high-quality and effective care.

Work package 2: feasibility study of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

- To conduct a process feasibility study of use of the Resource Kit in relation to practice, care outcomes and costs.
- To obtain feedback from participants about the acceptability and feasibility of the research procedures and measures employed.
- To refine the Resource Kit for use in a randomised controlled trial (RCT).

Work package 3: randomised controlled trial of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

- To evaluate the Resource Kit in practice by conducting a RCT with a representative sample of TMCDs across England, examining the impact upon hospital admissions, costs, and PwD, carers and staff compared with treatment as usual (TAU).

Methods

The three WPs were undertaken between 2014 and 2023, with activity seriously impacted by the COVID pandemic.

Work package 1: investigation of best practice in Teams Managing Crisis in Dementia, and development of the Best Practice Tool and Best Practice Resource Kit

A systematic literature review was undertaken, building on previous work, to investigate the impact of crisis teams for PwD on reducing hospital admissions and other related outcomes. An online scoping survey of managers explored the current use of older adult crisis teams in England to identify the range of different arrangements in place.

To examine current practice, qualitative studies were undertaken. Interviews were undertaken with 60 participants in 5 TMCDs. This involved 30 staff, 15 PwD and 15 carers. Qualitative questionnaires were also completed by 57 participants at a public engagement event to gain their understanding of crisis and preferences for service response. Focus groups were undertaken with 44 people, including TMCD staff, carers, PwD and other stakeholders, such as health and social care providers.

Data from the interviews and focus groups, systematic review and scoping survey were used to develop standards reflecting effective TMCD working. These standards were refined and reduced during a process of consultations, a 1-day consensus conference and modified Delphi process to produce a Best Practice Tool (BPT). This measured best practice and gave teams a score out of 100. It was field tested by 12 TMCDs and 5 Community Mental Health Teams (CMHTs) to examine scoring and validity.

From these standards, a Resource Kit was created containing a Home Treatment Package (HTP); the BPT; resources and training templates. The Resource Kit was tested by four teams over a 4-week period, after which feedback was obtained and the Resource Kit finalised for the feasibility study.

Work package 2: feasibility study of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

Four sites were recruited, each covering several teams, purposively selected from across England providing a total of 40 staff in TMCDs and 54 PwD and carers. TMCD staff completed online training in the use of the AQUEDUCT Resource Kit, and each team completed the BPT. Teams implemented the Resource Kit over an 8-week period and then, at the end, completed the BPT. Feedback was provided by team members. Information was collected at recruitment and follow-up from older people and carers using a range of measures. Data from the feasibility study were also reviewed by patient and public involvement and clinical staff reference group members to shape the trial and intervention design.

Work package 3: randomised controlled trial of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

Building on the literature, surveys, intervention design and feasibility study, a multisite pragmatic RCT was undertaken to compare the effectiveness and cost-effectiveness of the Resource Kit, used by TMCDs, with TAU.

A full RCT was undertaken across 24 TMCDs in England. Eligible teams were managing dementia mental health crises, offering urgent mental health assessment and intervention for PwD in the community. The primary outcome was admissions to psychiatric hospitals over a 6-month period in the geographical region of the TMCD, according to postcode, and was analysed using a Poisson regression model to estimate the treatment effect quantified by incidence rate ratio (IRR). Secondary outcomes related to PwD and their carers, and TMCD staff used multilevel mixed-effects models. Qualitative interviews and questionnaires with team members, PwD and carers were used to ascertain their experience of the intervention.

Results

Work package 1: investigation of best practice in Teams Managing Crisis in Dementia, and development of the Best Practice Tool and Best Practice Resource Kit

Seventy-four full-text articles were identified in the systematic review, and of these, three were included, plus four from a previous review. The systematic review demonstrated some indication of a positive effect of crisis teams on hospital

admissions, although there was a need for high-quality evidence and a full RCT. The material from the review also contributed towards the items defining standards of best practice used to create the BPT.

Sixty-two managers representing a range of areas in England undertook the online survey of TMCDs. Most managed CMHTs or Home Treatment Teams and reported considerable variation in ways of working. Both the systematic review and the scoping survey highlighted the need for a more standardised approach to managing crises for PwD in the community.

Qualitative work with staff, PwD, carers and other stakeholders indicated that services operated to a variety of models and that there was no clear shared definition of a crisis in dementia care. Carers particularly valued supportive interventions and crisis management that went beyond addressing the immediate pressure for hospital admission towards preventive goals such as improved coping strategies and talking through their lived experience. Thus, effective crisis intervention required accessible, expert services providing practical and emotional support, coordination with other services, and a person-centred approach that involves family members. The data from all these studies contributed to the development of standards for the BPT.

An initial 165 BPT standards were reduced and refined using consultation groups, a consensus conference and adjusted Delphi process. The final version of the BPT contained 50 items covered three areas: the crisis service, rapid assessment and intervention, and service resources. The BPT was field tested in early 2018 by 12 TMCDs and 5 non-crisis CMHTs and refined for the feasibility study.

Work package 2: feasibility study of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

The feasibility study was completed on time in March 2020, as the first period of lockdown associated with COVID-19 commenced. Findings indicated a degree of sensitivity to change over time of the BPT scores within teams, and different development choices by teams of domains in the Resource Kit. Due to non-use by teams the HTP was removed as a core feature of the Resource Kit. As expected, there were difficulties in recruitment and data collection from PwD and carers during crises. There was a positive response from staff in TMCDs. The choice of primary outcome as psychiatric hospital admissions was confirmed, with quality of life and well-being measures as secondary outcomes, reflecting the data collection environment imposed by COVID-19.

Work package 3: randomised controlled trial of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

Twenty-three TMCDs were successfully randomised from different geographical locations in England. For logistical purposes only, once consent was obtained, TMCDs were entered into a remote web-based randomisation system, which allocated them to either intervention or control arm with equal probability. This should not be confused with a cluster trial since the primary outcome data were collected at Team level. Blinding of TMCDs was not possible, but PwD, carers, outcome assessors and statisticians were blinded to TMCD arm allocation until the data analysis was completed. These included information from 238 staff and 75 PwD and their carers. Hence, staff members within the TMCDs were individually recruited, consented, and analysed as individual participants.

The intervention had no significant effect at the primary end point of 6 months on psychiatric hospital admissions. After adjustment for differences at baseline, the control group estimated IRR was 1.18, slightly, but not significantly, favouring the intervention group. The 95% confidence interval ran from 0.81 to 1.79 ($p = 0.37$). Adjusted analysis also showed no significant effect on secondary outcomes for PwD, their carers and staff. The intervention was well received by TMCD staff who engaged positively with the process. Qualitative work suggested that PwD and carers valued team clinical interventions, access to help in crisis and support from staff. However, there was a lack of cross agency integrated care.

Conclusions

The Resource Kit co-produced with staff, carers and PwD offers the possibility for audit, quality improvement and greater harmonisation of TMCDs with potential to improve support for PwD and their carers at home at critical times. There was visible staff commitment to service improvement in this area.

Recommendations for future research

Future work could examine quality improvement comparable to initiatives such as the Memory Services National Accreditation Programme in England, using the Resource Kit in conjunction with process measures more closely aligned to its immediate areas of impact.

Trial registration

This trial is registered as ISRCTN42855694.

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